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Bleiker, E.M.; Pouwer, F.; van der Ploeg, H.M.; Leer, J.H.; Adèr, H.J.

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Psychological distress two years after diagnosis of breast cancer: frequency and prediction

Eveline M.A. Bleiker^{a,*}, Frans Pouwer^a, Henk M. van der Ploeg^a,
Jan-Willem H. Leer^b, Herman J. Adèr^c

^aDepartment of Medical Psychology, Vrije Universiteit, Van der Boechorststraat 7, D 342, 1081 BT Amsterdam, The Netherlands

^bDepartment of Clinical Oncology, University Hospital Leiden, Leiden, The Netherlands

^cDepartment of Epidemiology and Biostatistics, Vrije Universiteit, Amsterdam, The Netherlands

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Abstract

The present prospective study aimed at (1) investigating the frequency of high levels of psychological distress in women with early-stage breast cancer almost two years after diagnosis and (2) identifying characteristics associated with long-term distress. One hundred and seventy women participated on two occasions. Two months after surgery, patients completed questionnaires measuring psychosocial variables (e.g., stressful life-events, health complaints, sleep problems, social support, subjective distress, personality factors), demographic and biomedical variables (e.g., TNM status, type of surgery). At the second measurement, subjective distress was assessed for a second time by means of the Impact of Events Scale (IES). Almost two years after diagnosis, 16% of the women reported a high level of psychological distress as measured by the Intrusion scale (IES). Best predictors of a high level of distress were: intrusive thoughts about the disease, trait-anxiety, health complaints and problems with sleeping. No significant association was found between previous life-events, social support or biomedical variables and levels of distress. © 2000 Elsevier Science Ireland Ltd. All rights reserved.

Keywords: Breast cancer; Psychological distress; Long term; Prospective design; Impact of event scale

1. Introduction

Being diagnosed with a life-threatening disease such as breast cancer induces a new situation in life which requires adjustment. In recent decades there has been a considerable amount of research which

aimed at identifying levels of distress. In previous studies on adjustment to breast cancer, it was found that about 20–30% of the women suffer from high levels of distress within the first year after diagnosis [1–3]. It was concluded that the majority of newly diagnosed women with breast cancer no longer experience serious psychological distress about one year after surgery [1].

Recently, a few studies reported on the prevalence of distress experienced in the year after treatment for

*Corresponding author. Tel.: +31-20-512-2523; fax: +31-20-512-2322.

E-mail address: ebleiker@nki.nl (E.M.A. Bleiker)

early stage breast cancer by using the DSM-IV criteria of PTSD (post traumatic stress disorder) [4]. The assessment of PTSD symptoms represent a somewhat different approach of measuring distress: ‘event-related-distress’, rather than ‘general distress’ is measured. The prevalence of PTSD symptoms one year after treatment for early stage breast cancer varied between 3 [5] and 12% [6]. Further research suggests that such psychological morbidity, if undetected, may be disabling and prolonged [7]. These findings raise the question of whether it is possible to identify characteristics of those women with breast cancer who are at risk for developing long-term (i.e., over one year after diagnosis) psychological distress.

We will briefly summarize findings about demographic variables, biomedical variables and psychosocial variables that are found to be associated with (usually short-term) psychological distress. First, age at diagnosis is usually found to be negatively related to distress [8–10]. Most studies show little relationship between marital status and psychiatric morbidity [11,12]. A positive relationship has been demonstrated between physical morbidity and psychological distress in cancer patients [13]. Taylor et al. [14] found poorer medical prognosis to be associated with poorer psychological adjustment. Several studies reported on the psychological impact of mastectomy versus breast conserving therapy. Most studies showed that mastectomy was related to a worse sexual adjustment and body image, but in most cases not to psychosocial adjustment [15–18]. An excess of psychosocial problems is observed in breast cancer patients undergoing chemotherapy [19,20].

Practical and emotional support are found to be positively related with good adjustment outcome [21]. Ganz et al. [22] reported that a psychosocial problems score was the best predictor of ‘psychosocial risk’ in the year after surgery (i.e., serious psychological, physical, treatment, relationship and vocational problems). Adjustment to breast cancer is found to be negatively related to the experience of premorbid life stress [23,24] and a history of depression [23]. In line with these results, optimism as a personality trait is reported to be positively related to good adjustment to breast cancer [25].

In summary, a small but significant part of newly diagnosed women with breast cancer experience

symptoms of distress. Although some studies have now been published on the experience of distress in the longer-term [26,27] most studies reported on levels of distress within one year after diagnosis. The aims of the present prospective study are to (1) investigate the frequency of high levels of psychological distress in women with early stage breast cancer almost two years after diagnosis and (2) identify characteristics associated with long-term distress.

2. Method

2.1. Subjects

Women receiving radiotherapeutic treatment at the University Hospital Leiden for early stage breast cancer ($N = 317$) were invited to participate in the study. Eligibility criteria to participate in the study were: a histological diagnosis of breast cancer (tumor stage $T_{1-4}N_{0-3}M_0$), either treated with mastectomy or breast conserving surgery, no previous neoplasms, younger than 75 years of age and sufficient knowledge of the Dutch language. A total of 77% ($N = 244$) of all eligible women participated in the study. The other women were not interested in participating in the study and since no informed consent was derived no information on their psychological or medical status was obtained. Our clinical impression is that non-participation had more to do with organizational issues than with patient characteristics.

2.2. Procedure

Between March 1991 and July 1993, all eligible women were invited by their treating radiotherapist to participate in the prospective study. The purpose and the contents of the study were explained to the patients in an informed consent letter. Patients were asked to complete a questionnaire twice, first under the supervision of a psychologist or a psychological assistant, at the University Hospital Leiden during the period of radiotherapy (T_1), and second 1 and 1/2 years after the first assessment (T_2), during a

visit of the psychologist/psychological assistant at the home of the patient.

2.3. Instruments

2.3.1. First measurement

At T1, the following demographic and biomedical variables were assessed: age, type of surgery (mastectomy/breast-conserving surgery), number of histological involved lymph nodes, adjuvant chemotherapy (yes/no) and adjuvant hormonal therapy (yes/no). The following psychological questionnaires were used:

A Dutch adapted version of the Holmes and Rahe [28] Social Readjustment Rating Scale was used to investigate whether the respondents had experienced specific life-events in the ten years prior to the breast cancer diagnosis. A list of 21 events was given. For each event the general question was posed whether this specific event had occurred to the respondent (yes/no), and if so, a four-point scale was used to indicate the subjective impact of that particular event (1 = no impact, 4 = severe impact). A sumscore was made including the number of events with a severe impact (3 or 4).

Data on sleep problems and health complaints were obtained by means of two scales of the Symptom Check List 90 (SCL-90) [29,30].

The Social Experiences Checklist (SEC) [31] was used to measure perceived social support. Two scores, measuring 'positive social interactions' as well as 'negative social interactions' were derived.

The so-called 'Self Assessment Questionnaire-Nijmegen' (SAQ-N) [32] is made up of reliable and valid scales, assessing personality traits [33]. For this study the following traits were assessed: anxiety (STAI) [34,35], anger (STAS) [36,37], depression (ZUNG) [38,39], rationality (acting in a rational and reasonable manner), anti-emotionality (an absence of emotional behavior or a lack of trust in one's own feelings) and understanding (trying to understand other people, despite negative feelings) [40,41], optimism (LOT) [42,43], emotional expression-in (i.e., feelings that are held in or suppressed), emotional expression-out (i.e., feelings that are directed toward other people or objects) and control of

emotions (i.e. control of outward expression of feelings) [41].

Cancer related distress was measured with the Dutch adaptation of the Impact of Event Scale (IES) [44,45]. This questionnaire consists of two subscales measuring intrusive thoughts and avoidance behavior. It assesses how the patient feels in the context of the experiences with a specific event, in this study 'breast cancer'. Intrusion and avoidance have been described as PTSD-symptoms. A subscale score of 0–8 is defined as a minor reaction, 9–19 as a moderate reaction and scores of 20 and above as a clinically important reaction [46,47].

2.3.2. Second measurement

To assess the levels of long-term cancer related distress, the IES was completed by the participants on average 21 months after surgery. Furthermore, they were asked to complete the Social Readjustment Rating Scale, rating the impact of possible stressful events that occurred to them during these past 21 months.

2.4. Statistical analyses

First, the frequency of high levels of distress was calculated by using descriptive statistics [51]. Secondly, a 'two-step procedure' was used to find the best predictors of long-term cancer related distress. We first performed explorative analyses to select variables related to levels of distress at T2. This was done with a randomly selected part of the sample that participated twice in the study (50%) called group A. Correlations between all possible predictors (assessed at T1) and the mean scores on the scales of the IES (intrusive thoughts and avoidance at T2) were computed by using Pearson's and Spearman's correlation methods. Then, variables that were found to be statistically significantly ($P < 0.05$) related to one or both IES scales (T2) were selected as possible predictors of long-term distress. A confirmative multiple regression analysis (backward) was used to test the predictive value of the selected variables in a new group of patients; the other 50% of the sample (group B). The use of this 'two-step procedure' (first

explorative analyses, then confirmative analyses) with two parts of the sample reduces the probability of getting ‘chance-findings’ [48].

3. Results

3.1. Subject characteristics

Of the invited women, 244 participated in the study at T1. The average time between breast surgery and the completion of the first questionnaire was two months ($SD = 0.8$). After an average period of 19 months ($SD = 2.4$) after T1, 200 women (82%) completed the second questionnaire (T2). Of the 44 non-participants, 24 refused to participate for a second time, ten had died and ten had moved to an unknown address. In 30 of the remaining 200 women, a recurrence of cancer was found before the second questionnaires were completed. Data from these women were excluded from the analyses, since adjustment to recurrence of cancer is found to be more problematic than adjustment to initial diagnosis [49].

In order to study possible selection bias due to non-response/drop-out, we compared the characteristics of women who participated twice ($N = 170$) with those of the women who participate only once ($N = 74$). No statistically significant differences were found between the groups for all demographic and psychosocial factors. As expected, those who ‘drop-ped-out’ had on average a worse prognosis (statistically significantly more often affected lymph nodes and more often mastectomy in stead of breast conserving therapy).

At T1, the mean age of the group that participated twice ($N = 170$) was 51.9 years, ranging from 29 to 75 years ($SD = 10.5$). Characteristics of these women are shown in Table 1. The majority of the women had low or intermediate education (76%). Most patients (81%) had a spouse/spouse equivalent. Furthermore, 70% of the patients were treated with breast-conserving therapy, whereas 30% had a mastectomy. Some women underwent chemotherapy (30%) and/or hormonal therapy (26%). The majority of the patients had no histologically involved lymph nodes (58%).

Table 1
Subject characteristics at first measurement ($N = 170$)

	Frequency ^a	Percentage
<i>Demographic variables</i>		
Age, years (mean \pm SD)	51.9 \pm 10.5	–
Educational level		
Low	76	45
Middle	53	31
High	41	24
Marital state		
Married/partner	138	81
Single	32	19
<i>Biomedical variables</i>		
Number of histological involved lymph nodes		
0	89	58
1–3	39	26
> 3	25	16
Type of surgery		
Breast conserving	111	70
Mastectomy	48	30
Chemotherapy		
Yes	45	30
No	104	70
Hormonal therapy		
Yes	37	26
No	106	74

^a Due to missing values not all variables add up to $N = 170$.

3.2. Psychological distress

Scores on each IES subscale equal to or above 20 can be considered as strong indicators of a significant stress response syndrome [44,46,50]. Table 2 shows that two months after surgery (T1), 16% of the patients scored equal to/above the cutoff score of 20 on the Intrusion scale, while 15% did so on the Avoidance scale. About 30% of the subjects reported moderate levels of intrusion and avoidance at T1. It was found that 21 months after surgery (T2), 16% of the patients reported high levels of intrusive thoughts (equal to/above 20), whereas 8% of the patients scored high on the Avoidance scale. Almost 60% of the patients who had high intrusion scores at the first measurement also scored highly at the second measurement. For the Avoidance scale this percentage was 20%.

Table 2

Levels of distress assessed with the two subscales of the IES (intrusion and avoidance) at two months (T1) and 21 months (T2) after breast cancer surgery ($N = 170$)

Distress	Classification	Cut-off score	% at T1	% at T2
Intrusion	high	≥ 20	16	16
	moderate	9–19	32	31
	low	≤ 8	52	53
Avoidance	high	≥ 20	15	8
	moderate	9–19	31	25
	low	≤ 8	54	67

3.3. Strongest predictors of long-term subjective psychological distress

To explore which of the psychological, demographic and biomedical variables reported within two months after surgery (T1) could best predict subjective psychological distress 21 months postsurgery (T2), Spearman's and Pearson's correlations were computed in group A ($N = 85$), between the depen-

dent variables (IES-scales at T2) and the possible predictors (see Table 3). These analyses yielded significant correlations between the scores on the *Intrusion-scale* (T2) and the following variables measured at T1: health complaints, sleeping problems, trait anxiety, trait depression, trait emotional expression-in, intrusion and avoidance. Age, trait anxiety, trait emotional expression-in and avoidance (all measured at T1) were significantly related to the

Table 3

Spearman's and Pearson's correlations of possible predictors (T1) and psychological distress (assessed with the two subscales: intrusion and avoidance) 21 months (T2) after breast cancer surgery in Group A ($N = 85$)

Possible predictors	Intrusion T2	Avoidance T2
Hormonal Therapy (Y/N)	– 0.08 ^a	0.17 ^a
Chemotherapy (Y/N)	0.04 ^a	0.19 ^a
Radical mastectomy (Y/N)	– 0.07 ^a	0.20 ^a
Stage (I, II, III)	– 0.09 ^a	0.22 ^a
Age	0.07	0.28*
Life events 3–10 years before diagnosis	0.09	– 0.04
Life events 0–3 years before diagnosis	0.17	– 0.00
Life events between T1 and T2	0.08	0.09
Health complaints (SCL-90)	0.37**	0.19
Sleeping problems (SCL-90)	0.39***	0.10
Negative social support (SEC)	0.19	0.16
Positive social support (SEC)	– 0.10	0.17
Anxiety (STAI-trait)	0.42***	0.24*
Anger (STAS-trait)	0.11	– 0.04
Depression (Zung)	0.32**	0.19
Optimism (LOT)	– 0.01	0.02
Rationality	0.01	– 0.02
Anti-emotionality	– 0.13	– 0.18
Understanding	0.13	0.19
Emotional expression-in	0.33**	0.38***
Emotional expression-out	0.16	– 0.00
Emotional control	– 0.07	– 0.00
Intrusion T1 (IES)	0.47***	0.13
Avoidance T1 (IES)	0.47***	0.31*

^a Spearman's correlation coefficient.

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.

scores on the *Avoidance-scale* measured at T2. Besides age, none of the demographic or treatment variables were significantly related to subjective psychological distress at T2.

To investigate the predictive value of the variables that were significantly related to (one of) the dependent variables, confirmative backward regression analyses were carried out on the data of the women in group B ($N = 85$). Table 4 shows that 48% of the variance of the *Intrusion-scale* (T2) was explained by three variables assessed at T1: intrusive thoughts, health complaints and sleeping problems. Partial correlation coefficients were 0.60, 0.30 and 0.29 respectively. Anxiety, depression, emotional expression-in and avoidance behavior (T1) were not found to be significant predictors of intrusion (T2) in group B.

Considering the significant intercorrelation between the *Intrusion-scale* (T1) and anxiety (T1) (0.33 in the present study), we expected that anxiety was also a significant predictor of psychological distress. Anxiety was entered after intrusion in the equation as a result of the selection-criteria of the backward regression procedure [44] and represented no substantial increase in the regression sum of squares and was therefore removed. In a new backward regression analysis, we removed the *Intrusion scale* (T1) firstly from the equation. As a result of this, anxiety appeared to be a significant predictor of intrusive thoughts (T2). This regression analysis resulted in the following predictors: health complaints ($\beta = 0.29$, partial correlation = 0.22) and anxiety ($\beta = 0.22$, partial correlation = 0.22). These two variables explained 19% of the variance of intrusion T2 (these results are not reported in Table 4).

Table 4
Prediction of distress (assessed with the intrusion-scale of the IES) 21 months post-surgery (T2)^{a,b}

Predictors at T1	Dependent variable: intrusion T2			
	β	T	Sign	Partial correlation
Intrusion T1	0.60	5.3	0.000	0.60
Health complaints	0.28	2.2	0.031	0.30
Sleep problems	0.25	2.1	0.043	0.29

^a Model obtained by multiple regression analyses (backward) in group B ($N = 85$).

^b Explained variance for group B was 48%.

Avoidance behavior at T1 was the only significant predictor of Avoidance behavior at T2; the partial correlation was 0.68 and the explained variance was 47%. When the *Avoidance scale* (T1) was excluded from the regression analysis, age appeared to be a small but significant predictor ($\beta = -0.25$, partial correlation = -0.25 , explained variance 6%; result not in Table 4).

4. Discussion

The first aim of the present study was to assess the frequency of high levels of cancer related distress in women with an early stage breast cancer almost two years after diagnosis. Results of the current study suggest that two months after surgery about one out of five breast cancer patients reported high levels of distress. These results are in line with the conclusions drawn in the review by Irvine et al. [1] in which it is stated that 20–30% of breast cancer patients experience severe psychological distress within the first year after diagnosis. At the longer-term follow-up, almost two years after diagnosis, again one out of five women reported a high level of intrusive thoughts about breast cancer. The level of intrusive thoughts seemed to be rather stable between both measurements; about 60% of the subjects who scored high at T1 scored also high at T2.

The results from this study are in contrast with the results as reported by Green et al. [5], who reported lower percentages of distress. This discrepancy may be due to the way of assessment: we used the IES as measure, they used a Structured Clinical Interview for DSM-III-R to assess PTSD-symptoms. The use of different instruments at different points in time may explain differences between the levels of distress. It is therefore important to notice that, depending on the severity of the criteria of 'distress', we might come to different conclusions with regard to the frequency of the occurrence of distress. When, for example, the criteria for PTSD were used, we would have come to lower percentages. It is therefore important to use similar instruments in various studies in order to make meaningful comparisons. The IES is one scale that is now commonly used to assess levels of distress and we would encourage the use of this questionnaire to facilitate comparisons

between the results of several studies. The present study provides important data for this questionnaire for a Dutch breast cancer population. These data may be helpful to relate to in future studies.

What is the meaning of a number of 16% that reports to the experience of high levels of distress or symptoms of PTSD? According to a review of the literature, 20–25% of persons who are exposed to traditional stressors such as rape, assault or combat meet the criteria for PTSD [52]. In the general population, PTSD is present in about 1% of the total population [53]. A total of 16% of breast cancer patients who report symptoms of PTSD is therefore considered of significant importance.

The second aim of the study was to identify characteristics associated with distress experienced over a period of time that exceeds the first year after diagnosis. Patients who reported on average (1) a large number of intrusive thoughts about breast cancer (e.g., ‘thinking about breast cancer when I did not mean to’), (2) a large number of health complaints (e.g., headache, dizziness, back pain, difficulty with breathing) and/or (3) problems with sleeping (e.g., difficulties with falling asleep) at T1, appeared to be at risk for experiencing high levels of distress two years after diagnosis. Patients with an anxious personality were also at risk for long-term psychological distress.

The finding that health complaints were predictive of psychological distress was found in other studies [6,13,26,47,54] and can be explained by the hypothesis that a large number of health complaints will result in worries about a recurrence of the cancer or preoccupations with the body and/or loss of confidence in the body and, as a consequence of this, lead to a higher level of distress.

The results of the present study do not provide support for findings that the type of surgery has a significant impact on the level of distress of breast cancer patients [14,55], but are in line with the findings of Schain et al. [56]. These authors reported that patients with breast-conserving surgery and patients with radical mastectomy did not differ with regard to distress at 12 months and 24 months follow-ups. Finally, our results do not support the hypothesis that social support (positive and/or negative) and/or previous life events have a major impact on the level of long-term psychological distress.

We conclude that a small but significant proportion of the breast cancer patients in our study were at risk for severe long-term psychological distress. These women were on average characterized by an increased level of anxiety and intrusive thoughts about breast cancer, a large number of health complaints and sleeping problems shortly after surgery. A limitation of the generality of these findings is that the subjects in our study had early-stage breast cancer with a good prognosis. Therefore, these results cannot be generalized to other populations (e.g. patients with advanced cancers, patients with a recurrence of cancer or patients with other cancers). We expect that the percentage of patients with high levels of distress will be higher in women with a worse prognosis. This was found in the study by Kaasa et al. [47] who reported high levels of intrusive thoughts and avoidance ≥ 20 in 33 and 35% of cancer patients with advanced disease, respectively.

Oncologists and other health care workers should be aware that almost half of the group of breast cancer patients may suffer from moderate to severe psychological distress, even though they have early-stage breast cancer with a relatively good prognosis. They should be aware that these feelings and accompanying signs and symptoms may continue to be the case even two years after treatment in patients without signs of distant metastases. Further studies should investigate whether women with these characteristics will benefit from additional support in order to prevent long-term psychological morbidity.

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